

104TH CONGRESS
1ST SESSION

S. 1442

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

IN THE SENATE OF THE UNITED STATES

DECEMBER 4, 1995

Mr. JOHNSTON introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To authorize the Secretary of Health and Human Services to award a grant for the establishment of the National Center for Sickle Cell Disease Research, and for other purposes.

1 *Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

3 **SECTION 1. FINDINGS AND PURPOSE.**

4 (a) FINDINGS.—Congress finds that:

5 (1) Sickle Cell Disease is a serious illness that
6 disproportionately affects African-Americans.

7 (2) Approximately 1 out of every 12 African-
8 Americans is born with the sickle cell trait, and

1 about 1 out of every 600 is afflicted with Sickle Cell
2 Disease.

3 (3) Sickle cell conditions also occur in other
4 United States populations, primarily those of Puerto
5 Rican, Cuban, southern Italian ancestry and more
6 recently sickle cell has been found in some Cauca-
7 sian individuals.

8 (4) Sickle Cell Disease is a painful and dis-
9 abling disorder which can lead to untimely death
10 and is caused by inadequate transportation of oxy-
11 gen due to an abnormal type of hemoglobin molecule
12 in the red blood cells.

13 (5) Sickle Cell Disease is an inherited disease
14 which can be transmitted to offspring, particularly if
15 both parents carry the genetic trait.

16 (6) The sickle cell trait carriers show no sign of
17 the disease, but statistically, 1 in 4 of their children
18 will be afflicted with the disease.

19 (7) There is no national research center devoted
20 to Sickle Cell Disease in the United States.

21 (8) There is no known cure for Sickle Cell Dis-
22 ease at this time and there is a need for prioritized
23 and specialized research to find such a cure for this
24 severely disabling disease.

(9) Louisiana's minority population is 1,299,281.

3 (10) Of this number, a suspected 3,248 individuals
4 will have the disease and of those individuals,
5 25 percent (812 individuals) will have the most
6 acute and serious stage of Sickle Cell Disease, a
7 stage that is usually fatal.

(11) Some 129,928 individuals in Louisiana will carry the sickle cell trait.

(12) Southern University, located in Baton Rouge, Louisiana is the largest predominately African-American university in the United States.

(13) Approximately 16,700 students attend this 112 year old school and Southern graduates are located throughout the United States and the world.

16 (14) The State of Louisiana through the Lou-
17 isiana Legislature and Southern University, has
18 shown great leadership and committed significant fi-
19 nancial and personnel resources towards the develop-
20 ment of a National Center for Sickle Cell Disease
21 Research.

22 (15) Because Southern University has committed its resources and personnel to seeing this project through to its ultimate goal, finding a cure for Sick-
23 le Cell Disease, and because of Southern University's
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25

1 sity's large minority population it is appropriate to
2 locate the National Center for Sickle Cell Disease
3 Research at Southern University in Baton Rouge.

4 (b) PURPOSE.—It is the purpose of this Act to establish
5 a National Center for Sickle Cell Disease at Southern
6 University in Baton Rouge, Louisiana, that will have the
7 following objectives—

8 (1) to conduct biomedical research and clinical
9 investigations designed to find a cure for Sickle Cell
10 Disease;

11 (2) to conduct a wide variety of human behavioral
12 studies designed to provide new knowledge
13 about such issues as the effectiveness of various
14 counseling and education methods, and techniques to
15 improve coping skills on the part of patients and
16 their families;

17 (3) to establish collaborative arrangements and
18 joint research programs and projects with other
19 Louisiana institutions of higher education, such as
20 Louisiana State University Medical Centers at New
21 Orleans and Shreveport and Tulane University Medical
22 Center to conduct clinical trials on anti-sickling
23 agents;

24 (4) to provide expanded opportunities for faculty
25 members at the institutions described in para-

1 graph (3) to publish in the three broad areas of
2 basic biomedical research, psychosocial research and
3 clinical research;

4 (5) to become a laboratory for training both
5 graduate and undergraduate students in research
6 methods and techniques concerning Sickle Cell Dis-
7 ease; and

8 (6) to develop, promote and implement joint re-
9 search projects with other public and private higher
10 education institutions including teaching hospitals
11 on Sickle Cell Disease.

12 **SEC. 2. NATIONAL CENTER FOR SICKLE CELL DISEASE RE-**
13 **SEARCH.**

14 (a) GRANT.—The Secretary of Health and Human
15 Services shall award a grant to the Louisiana Department
16 of Health and Hospitals for the establishment and con-
17 struction of the National Center for Sickle Cell Disease
18 Research at Southern University in Baton Rouge, Louisi-
19 ana, and for related facilities and equipment at such Cen-
20 ter. Prior to the awarding of such grant, the State of Lou-
21 isiana shall certify to the Secretary—

22 (1) that the State of Louisiana has provided
23 not less than \$7,000,000 to support and operate
24 such Center; and



4 (b) AUTHORIZATION OF APPROPRIATIONS.—There is
5 authorized to be appropriated \$21,000,000 to carry out
6 the purposes of this Act.

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